

The Consumer-Directed Health Care: Challenges and Opportunities for Families with Youth with Serious Emotional Disturbance

by

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Introduction

Recognition of the need for greater consumer direction in health care decision making is growing in both the commercial and public sectors. The final report of the President's New Freedom Commission on Mental Health identifies six goals for the transformed mental health system; one of these goals is that mental health care is consumer and family driven (New Freedom Commission on Mental Health, 2003). The report recommends placing funding for services, treatment, and supports increasingly under the management of consumers and families as one way to enhance choice. In the area of children's behavioral health care, the value of family-driven services has been a key component of children's systems of care for the past two decades. The importance of valuing the families of these youth and building on their strengths has been widely endorsed in the children's mental health field (Cheney & Osher, 1997; Karp, 1993; Koroloff, Friesen, Reilly, & Rinkin, 1996). Friesen & Koroloff (1990) have provided practice guidelines for a treatment approach that is premised on the importance of partnering with parents with a child with serious emotional problems.

Consumer-directed health care is an emerging element of many commercial health plans that can take many forms, such as spending accounts or health reimbursement arrangements, but has a single goal: to increase the knowledge and choices of consumers in purchasing health care services (Dougherty, 2003). The premise of consumer direction is that health care would be more efficient if consumers had fiscal incentives to choose more cost-effective care. Consumer direction means that consumers conduct a self-assessment of their health needs with appropriate advice and guidance, decide how and by whom these needs can best be met, and monitor the quality of the services they choose. An important component of consumer direction is that consumers have access to effective education, including an array of decision support tools. For example, consumers need information about the evidence base for their treatment needs and an understanding of how to recruit and select providers and monitor the quality of the services they select.

The purpose of this paper is to examine the impact of consumer direction on families and youth in families with a child with serious emotional problems. A brief review of the status of children's mental health services, including the concept of systems of care and behavioral health financing trends and challenges, contextualizes the issue. The potential range of issues raised by consumer-driven care is identified, drawing upon what has been learned from other major changes in behavioral health care financing and organizational arrangements, including managed care. Finally, a set of recommendations and action steps are proposed, including values and principles associated with consumer direction for families with a child with serious emotional disturbance.

This paper addresses the impact of consumer-directed care on the population of children with serious emotional problems and their families. Although many of the issues and opportunities presented by consumer direction are the same for various populations, population-specific challenges will be highlighted in this paper. The term “consumer” is used to refer to parents of children with serious emotional problems; it is assumed that as a child with serious emotional problems approaches later adolescence, the youth him or herself will take on the role of consumer.

The Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration (SAMHSA) has established a Federal definition for children with serious emotional problems. According to this definition, children with serious emotional disturbance are “persons from birth up to age 18 who currently or at any time during the past year have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within DSM-IV; and that resulted in functional impairment which substantially interferes with or limits the child’s role or functioning in family, school, or community activities (*Final notice establishing definitions for (1) children with a serious emotional disturbance, and (2) adults with a serious mental illness*, 1993, p. 29425). Since the introduction of the Federal definition, States have been required to use its broad parameters to develop their own definitions of children with serious emotional problems.

Background

In the public sector, two reforms of children’s behavioral health services are dominant over the past 20 years: the system of care movement and new financing arrangements, including Medicaid behavioral health managed care. This section reviews these reforms.

Systems of Care

In her seminal work, *Unclaimed Children*, Knitzer (1982) highlighted serious problems in children’s mental health services that a number of government reports also have described. These challenges included the high level of unmet needs among children and youth with mental health problems, an overreliance on inpatient and residential care, the lack of community-based supports and services, a lack of accountability for this population, and a lack of collaboration between the systems serving these youth and their families. The proposed remedy for these challenges was the promotion of comprehensive community-based services, known as systems of care.

Systems of care were originally defined (Stroul & Friedman, 1986) as “a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing

needs of children and their families.” The core values of systems of care are that services should be community based, child centered, family focused, and culturally competent. These are the guiding principles for systems of care (Stroul & Friedman, 1986; Stroul & Friedman, 1996):

- Comprehensive
- Individualized to each child and family
- Provided in the least restrictive, clinically appropriate setting
- Coordinated at both system and service delivery levels
- Families and youth involved as full partners
- Early identification and intervention emphasized

The Center for Mental Health Services at SAMHSA has provided leadership and funding for the development of systems of care in communities throughout the country through the Comprehensive Community Mental Health Services for Children and Their Families Program. This initiative has offered natural opportunities for diverse communities to implement systems that incorporate these principles, including two principles (individualized care and family and youth involvement) that demand that families and youth play a larger role in managing their treatment and support services. The challenges identified, lessons learned, and recommendations from these communities are included in the Key Issues and Recommendations sections of this paper.

Recently, the system of care concept has been reexamined and clarified (Stroul, 2002). Stroul defines system of care more broadly to include three essential elements: a range of treatment services and supports, a guiding philosophy of values and principles, and a supporting infrastructure. This paper uses the elements of this definition as the framework for consumer-directed care for these populations.

Managed Behavioral Health Care

Trends over the past two decades in public sector financing of children’s behavioral health services include the adoption of a health insurance model from the private sector, the introduction of behavioral health managed care for Medicaid services, the development of provider networks, and the availability of funding through the State Children’s Health Insurance Program (SCHIP) and the Federal Temporary Assistance for Needy Families program (TANF). The consequences of these disparate trends in financing policy is a system that has been described as both irrational and contradictory (Cole & Poe, 1993).

The most significant trend in public sector financing of mental health services over the past two decades is the adoption of managed care. According to the 2003 State Survey of the Health Care Reform Tracking Project, only five States over the past decade have never implemented a managed care system for children’s behavioral health services (Stroul, Pires, & Armstrong, 2004). Out of

45 States and the District of Columbia that have implemented managed care, 38 (86 percent) are still involved in managed care. Most managed care systems in 2003 (77 percent) include substance abuse, with integrated systems being more likely to do so. When substance abuse is not included, it remains fee-for-service in 78 percent of the systems. In the remaining systems, it is either a separate carve out or included in a physical health managed care arrangement that does not include mental health. These trends mirror the reforms over the past two decades in the national health care delivery system.

The use of an integrated model for the financing and administration of health and behavioral health services is one of two primary managed care approaches adopted by States. As State Medicaid authorities confronted escalating health care costs in the 1980s and early 1990s, many States turned to private sector solutions, including a commercial health insurance model and a number of managed care approaches. The private sector health insurance model is based on an acute care health delivery system. Health and behavioral health services are typically administered and financed jointly through Health Maintenance Organizations (HMOs), and HMOs often subcontract with Behavioral Health Organizations (BHOs) for the provision of mental health services. Mental health coverage in this integrated model is typically limited to acute inpatient care, a small number of outpatient visits per year, and psychotropic medication.

The integration of health and behavioral health services and the limits on service coverage and utilization are dramatic changes from the traditional fee-for-service Medicaid system which typically included a much larger array of children's behavioral health services and no limits on the number and types of visits and services. In States that use this integrated managed care approach, the administration and financing of services for children with serious and complex behavioral problems, except for a limited acute care benefit, is often left out of health insurance plans and managed by the State mental health authority.

In the second approach, a carve-out design, behavioral health services are financed and administered separately from physical health services. In a study comparing the differential impact of integrated and carve-out designs (Pires, Stroul, & Armstrong, 2000), it was found that States with carve-out or partial carve-out designs tend to cover a broader array of children's mental health services, offer more home and community-based services, and allow greater flexibility in service delivery than States with integrated designs. A number of factors contribute to the relative strengths of a carve-out, including protection of the funding for behavioral health services, easier blending of Medicaid with non-Medicaid dollars, a greater likelihood that savings will be reinvested into children's mental health services, and greater involvement of agencies and individuals with expertise in child behavioral health policy. As we move in the direction of consumer-directed care, we need to address the implementation issues related to both integrated and carve-out managed care designs, and to analyze the differential effects of each design.

The Federal Balanced Budget Act of 1997 includes Title XXI of the Social Security Act, which established SCHIP. Using Federal grants and matching State funds, this program provides comprehensive health insurance for children whose family incomes are above the Medicaid eligibility level and below 200 percent of the Federal poverty level. The Federal legislation requires that children with emotional or substance abuse problems must be offered the following services: outpatient hospital services, including partial hospitalization; inpatient hospital services; physician services; and Early and Periodic Screening, Diagnosis, and Treatment (EPSDT).

Despite the opportunities presented by the SCHIP, there are a number of challenges. First, the limited mandated array of behavioral health services might not meet the needs of children with serious and complex behavioral health problems. A second dilemma is in the use of EPSDT screenings to identify children with mental health problems. Many States do not include behavioral health assessment questions in their EPSDT screening instruments. In addition, many pediatricians and public health professionals who conduct EPSDT screenings are not adequately trained in the detection of behavioral health problems.

In addition to Medicaid, general revenue funds, and SCHIP, funding for children's behavioral health services is often located in other child-serving systems, including schools, child welfare, and juvenile justice. Some States are also using TANF funds for children's mental health services in families where a child's emotional problems are an obstacle to the mother's employment. The availability of funding in other systems may be intended to create a safety net outside of managed care reforms, but the disparate funding sources often lead to fragmentation, duplication, and lack of coordination of care.

Over the past 10 years, a number of advocates have recommended cross-system reforms in financing policy that would promote blended funding. Blended funding is an agreement to pool behavioral health funding resources, either at the State or local level, with the goals of promoting care coordination and flexible service delivery that is family driven rather than driven by categorical funding streams. Although conceptually appealing, few States or communities have been successful in actual pooling of funds. One exception is Milwaukee Wraparound, a system of care for children with serious emotional problems that blends funds from Medicaid, general revenue, child welfare, and juvenile justice. Another approach is braided funding, defined as an attempt to carefully coordinate payment for services at a local system level without actual pooling of funds. The achievement of either blended or braided funding continues to be an elusive goal. In the development of the Centers for Medicare and Medicaid Services (CMS) home and community-based waiver sites and consumer-directed care, pilots should encourage the option of braided funding.

Key Issues

Our experience over the past 15 years with the implementation of systems of care and public sector behavioral health managed care provides a number of lessons learned regarding key issues that need to be addressed as we transition to consumer-directed health care.

Federal and State Leadership and Direction

The role of Federal and State policymakers is leadership and direction in establishing a vision, values, and goals for consumer-directed health care. An important element of leadership for this new initiative is to implement evaluation and accountability mechanisms at pilot sites and then to disseminate the findings to other States and communities.

Families and Youth at the Planning Table

One of the hallmarks of the consumer movement is “Nothing about us without us.” Families and youth need to be full participants in both Federal and State level planning activities for consumer-directed care. Their voice and guidance are essential as we examine issues such as choice, the service array, budget management and accountability mechanisms, cash flow and carryover of funds, protocols and practice standards, quality assurance, and provider/vendor availability and development.

Education for Families, Youth, Providers, and Other Child-Serving Systems

Despite the progress that has been made towards family-driven and individualized care, the notion that families and/or youth will choose and purchase treatment and support services will be a major change for families, youth, providers, schools, case managers, and practitioners. Ongoing training, consultation, and technical assistance will be needed for all these stakeholders, including training on individualized care and the wraparound process, cultural competence, evidence-based practices, monitoring the quality of care, and partnerships with families and youth.

Service Capacity

One of the challenges of reforming the children’s behavioral health care system is the current level of unmet need for children’s mental health and substance abuse services. Service capacity is limited, and many communities have waiting lists both for traditional services, such as outpatient care, and for community-based services and supports. A common experience in the CMHS system of care communities is that as services become more individualized and family driven, the identified need grows for support services such as respite, mentoring, tutoring, and behavioral aides. Capacity development in these areas is

challenging due to staff shortages, difficulty in finding resources, and lack of certification and training standards.

Access

Research and evaluation studies have found that families of youth with serious and complex behavioral health problems need ongoing access to a broad and flexible array of treatment services and supports. A local governing body or management entity with family and youth participants needs to develop and monitor a plan for how families can easily access a flexible and comprehensive array of services.

Service Coordination/Role of Case Manager

As communities move towards family and youth-driven care, the traditional role of the case manager changes dramatically. The case manager is no longer in charge of setting direction and planning for the child's care. Instead, case managers need to take on the tasks of facilitation and support, family and youth education about resource availability, assurance of clinical oversight of case plans, and the development of informal supports and services for both the youth and family. The case manager also is responsible for negotiation, dispute resolution, and liaison roles with other child-serving systems. A related issue is whether case managers will be responsible for fiscal tasks, such as advising families on budgeting and spending plans, reviewing spending plans, and monitoring uses of voucher funds. If case managers are not directly responsible for fiscal tasks, communication and coordination with whoever is responsible will be important tasks of the case manager.

Interagency Collaboration

Youth with serious behavioral mental problems often have involvement with many other systems, including juvenile justice, primary health care, special education, and child welfare. Often their behavioral health services are paid for by these systems. For example, a youth's Individual Educational Plan (IEP) may pay for psychiatric consultation. When other child-serving systems do not understand and/or embrace consumer direction, confusion and conflicts may occur.

Impact on Providers

One result of the advent of managed care is structural and organizational changes in the children's mental health provider community, including the development of provider networks—associations of providers and practitioners who agree to lower than usual reimbursement arrangements in order to access clients enrolled in managed care plans (U. S. Department of Health and Human Services, 1999). The incentives to develop provider networks have tended to

result in an expanded range of providers, including the credentialing of new types of practitioners, new types of providers, and new services included in the benefit plan.

The introduction of managed care has had many other effects on behavioral health providers, including an increase in financial risks and administrative burden, and changes in credentialing and licensing requirements. The advent of consumer-driven care will be another major change to the extent that it is another step towards a market-driven environment. Previous studies of consumer-directed models of personal care indicate that consumer choice and satisfaction is facilitated when consumers can hire whomever they wish and that consumers tend to hire persons with whom they are familiar, such as family members, friends, and neighbors (Doty, Kasper, & Litvak, 1996). This change will be threatening to some providers due to the possibility of their losing their customer base. Providers need to be involved as key stakeholders in the movement towards consumer direction.

Assuring Quality

One question that arises as we move towards consumer direction is “Who is vouching for quality?” As noted earlier, families with a child with serious emotional problems who are given the choice often select informal support providers, including family members and friends, to offer respite, mentoring, and in-home behavioral services. Agreements need to be made regarding standards for credentialing and certifying individual vendors, who will certify them, and how quality will be documented and monitored. Similar quality assurance and accountability decisions need to be made regarding services offered by provider agencies.

Cultural Competence

Cultural and racial disparities in behavioral health access are an historical problem that should be monitored as we move towards consumer-directed care (U.S. Department of Health and Human Services, 2001). Decisions need to be made at the State and local levels regarding how to monitor cultural disparities and who will be accountable for strategies to address disparities in consumer-directed care. Strategies need to include monitoring of penetration rates for various cultural groups, outreach to culturally diverse communities, training and consultation for clinicians and case managers, and integration of primary and mental health care.

Financing

Consumer-directed care raises a number of financing questions. For example, how will funding levels for vouchers and spending accounts be determined? Will families and youth be able to “roll over” funding from month to month and from

year to year? Youth with serious emotional problems often relapse and/or experience crisis periods when higher levels of service intensity and dosage are needed. How will providers and individual vendors receive the start-up funds needed for activities such as program development and meeting certification, training, and credentialing requirements?

Recommendations and Action Items

This final section of the paper proposes a recommendation and set of action steps for each issue identified above. These recommendations will serve as a guide for the implementation of consumer-directed care for families with a youth with serious emotional disturbance.

Federal Leadership and Direction

Recommendation: SAMHSA and CMS, in partnership with other Federal agencies, will provide leadership and direction in the arena of consumer-directed behavioral health care.

Action Steps

- Create a vision for consumer-directed behavioral health care, including systems of care values and principles.
- Develop a national infrastructure for implementation of consumer-driven care, including model identification, specification, and dissemination.
- Pilot and evaluate different models of consumer-directed care for children with serious emotional problems and their families, using communities that are culturally and racially diverse.
- Examine cross-agency Federal funding streams for children's behavioral health services with the goal of a more integrated financing policy across Federal agencies.
- Allow CMS waiver communities and pilot consumer direction sites to integrate Federal funding streams in the creation of voucher spending plans.
- Develop a minimum set of performance standards and quality measures for children's behavioral health services, building on the efforts of the Outcomes Roundtable for Children and Families and the Forum on Performance Measurement in Behavioral Healthcare.

Families and Youth at the Planning Table

Recommendation: Mandate that families and youth with serious emotional problems be included on planning and oversight structures for consumer-directed care.

Action Steps

- Formally support and pay family organizations for planning, consultation, and technical assistance roles.
- Create protocols, standards, and practice guidelines for family and youth directed care.
- Use family members to provide family education regarding choice of providers and vendors, referral sources, and budget management.
- Provide families and youth with information on evidence-based and promising practices.
- Use family organizations, parents, and youth to develop and implement quality assurance plans.
- Include family members in the development of licensing and certification requirements for new services, such as respite, mentoring, and behavioral aides.

Education for Families, Youth, Providers, and Other Child-Serving Systems

Recommendation: Provide funding and instructional mechanisms for education, technical assistance, and ongoing consultation with key stakeholders, including families, youth, provider agencies, vendors, case managers, clinicians, and major child systems.

Action Steps

- Develop and pilot curricula and training materials on topics related to consumer direction, including individualized care and the wraparound process, cultural competence, evidence-based practices, monitoring the quality of care, and partnerships with families and youth. Families and youth, for example, may need educational support in the areas of provider selection, evidence-based treatment recommendations, the effects of various psychotropic medications, how to develop and use informal supports, and budget management.
- Involve families and youth in curriculum development and the selection of dissemination tools.
- Make educational materials available through various modalities, including CDs and Web-based instructional methods.

Service Capacity

Recommendation: Include a broad and flexible benefit design in consumer-directed care models for families with youth with behavioral health needs.

Action Steps

- Include both treatment and support services in voucher plans.
- Clearly define the covered services and supports.

- Make support services, e.g., respite, available for both the youth and caregivers.
- Set aside new funds for service capacity development.
- Allow for reinvestment of savings into service capacity development.
- Make provisions for community capacity development of new treatment and support services, as families and youth identify the need for additional services.
- Allow families and youth to develop the purchasing specifications for new services and supports.

Access

Recommendation: At both State and local levels, appoint a management entity or governance structure that is responsible for ensuring that families and youth have ongoing and ready access to a flexible array of supports and treatment services.

Action Steps

- At pilot sites, experiment with the use of family advocates whose role is to help families and youth access appropriate assessments, services, and supports.
- Develop methods to assess family and youth satisfaction about access.

Service Coordination/Role of Case Manager

Recommendation: Include all stakeholders, including case managers, families, and youth, in an examination of the appropriate case manager roles and tasks in a consumer-driven behavioral health care system.

Action Steps

- Identify and describe case manager tasks in communities where family-driven care is reportedly taking place.
- At pilot sites, train and support case managers in such tasks as facilitation and support, family and youth education about available services and resource development, clinical oversight of case plans, and negotiation, dispute resolution, and liaison roles with other child-serving systems.
- At pilot sites, experiment with case managers assuming fiscal tasks, such as advising families on budgeting and spending plan development, reviewing spending plans, and monitoring uses of the voucher funds.

Interagency Collaboration

Recommendation: At Federal, State, and local levels, use existing structures or develop new mechanisms to communicate with other child-serving systems regarding consumer-directed care.

Action Steps

- Involve cross-agency partners at the Federal, State, and local levels in planning structures and activities for consumer-directed care.
- Provide education and training about consumer-directed care for the leadership of child-serving systems.
- Include program directors, supervisors, and line staff from other systems in ongoing education and technical assistance activities.
- Develop interagency mechanisms for communication, problem solving, and decision making regarding consumer-directed care.

Impact on Providers

Recommendation: Include children's mental health providers and vendors as partners in the planning, implementation, and refinement of consumer-directed care.

Action Steps

- Involve behavioral health providers in planning structures and activities.
- Provide education about consumer-directed care for the leadership of provider agencies.
- Provide technical assistance and support to providers regarding modifications to information and referral systems, billing and payment mechanisms, Management Information Systems (MIS), and reporting requirements.
- At the local management level, develop mechanisms for communication, coordination, and problem solving with behavioral health providers and vendors.

Assuring Quality

Recommendation: Within consumer-directed care, develop and implement a set of children's behavioral health quality and outcome measures and indicators.

Action Steps

- Involve key stakeholders in the development of a set of children's behavioral health outcome measures and indicators.
- At the pilot sites, develop monitoring and information systems for service utilization, satisfaction, cost, outcomes, and quality.

- Involve family members, youth, and family organizations in the design and implementation of quality improvement programs.
- At the pilot sites, experiment with the use of provider/vendor report cards that are shared with families and youth.
- Create mechanisms to collect common data elements from multiple systems, including mental health, substance abuse, Medicaid, juvenile justice, child welfare, and schools.

Cultural Competence

Recommendation: Develop strategies to monitor and address racial and ethnic disparities in access to and utilization of behavioral health services and supports in consumer-directed care.

Action Steps

- Establish accountability at State and local levels for monitoring racial and ethnic disparities in access and service utilization.
- Provide outreach to culturally diverse populations and communities.
- Ensure that culturally and linguistically diverse providers and vendors are available in communities.
- Provide start-up funds for indigenous and ethnically specific services and supports, such as traditional healers, cultural brokers, and faith-based organizations.
- Provide funds for evaluation that creates an evidence base for the effectiveness of cultural modalities.

Financing

Recommendation: Develop a financing plan for consumer direction with the goals of ensuring the adequacy of fiscal resources, accountability, and reinvestment of savings into children's behavioral health services.

Action Steps

- Use cost data from existing MIS systems and research studies to set the funding levels for vouchers. Given the lack of experience with consumer direction, build into the system flexibility in making rate adjustments.
- Allow families and youth to "roll over" a proportion of funding from month to month and from year to year.
- At the CMS waiver sites and the consumer direction pilots, experiment with risk-sharing arrangements that align with the goals of consumer-directed care.
- Include funds to invest in service capacity development.
- Mandate that any annual savings be reinvested into children's behavioral health services.

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